The quality of life of people with mental retardation. In search of an adequate approach.

Vreeke, G.J.; Janssen, C.G.C.; Resnick, S.; Stolk, J.

published in
International Journal of Rehabilitation Research
1997

DOI (link to publisher)
10.1097/00004356-199709000-00005

document version
Publisher's PDF, also known as Version of record

International Journal of Rehabilitation Research **20**, 289–301 (1997)

The quality of life of people with mental retardation: in search of an adequate approach

G.J. VREEKE*, C.G.C. JANSSEN, S. RESNICK and J. STOLK

Vrije Universiteit, Faculty of Psychology and Pedagogical Sciences, Amsterdam, The Netherlands

There is a lack of instruments that measure the quality of life of people with mental retardation. These types of instruments could be used in order to give an indication of the quality of care they receive. At the moment we are developing an instrument that measures quality of life. Our first task is to find an adequate definition of 'quality of life'. In this article an attempt is made to define this term as it relates to people with mental retardation. Starting from literature in the field of disabilities, reflections in the social sciences and philosophical analysis, a combined approach is adopted, according to which quality of life consists of specific objective and subjective factors.

Die Lebensqualität geistig behinderter Menschen – Auf der Suche nach einem adäquaten Zugang

Für eine Messung der Lebensqualität von Menschen mit geistiger Behinderung liegen geeignete Instrumente noch nicht vor, mit deren Hilfe Hinweise zur Qualität der Betreuung dieses Personenkreises gewonnen werden könnten. Ein solches Instrument zur Lebensqualitätsmessung wird derzeit von uns entwickelt, wobei es eine unserer ersten Aufgaben ist, eine geeignete Definition von „Lebensqualität" zu finden. Der vorliegende Beitrag ist ein Versuch, diesen Begriff in bezug auf Menschen mit geistiger Behinderung näher zu umreißen. Auf der Grundlage einschlägiger Veröffentlichungen, sozialwissenschaftlicher Überlegungen und philosophischer Analyse wird ein integrativer Ansatz formuliert, demzufolge Lebensqualität spezifische objektive und subjektive Faktoren vereint.

La qualité de vie des personnes déficientes mentales: à la recherche d'une approche adéquate

Il existe un manque d'outils d'évaluation de la qualité de vie des personnes déficientes mentales. Ce genre d'outils pourrait servir à fournir une indication sur la qualité de leur prise en charge Nous sommes actuellement entrain de développer un outil destiné à évaluer la qualité de vie. Notre première tâche consiste à trouver une définition adéquate de « qualité de vie ». Dans cei article, on tente une définition de ce concept tel qu'il convient pour des personnes présentant un retard mental. En partant du champ littéraire du handicap, de la réflexion des sciences sociales et des analyses philosophiques, une approche combinée a été adoptée en rapport avec ce que la qualité de vie présente d'objectifs spécifiques et de facteurs subjectifs.

Candidad de Vida de las personas con Deficiencia Intelectual

Faltan instrumentos para medir la calidad de vida de las personas con deficiencia intelectual. Tales instrumentos podrian usarse para facilitar indicaciones sobre la calidad de la asistencia que se les

*Address for correspondence: Vrije Universiteit, Faculty of Psychology and Pedagogical Sciences, Van der Boechorstraat 1, 1081 BT Amsterdam, The Netherlands

presta. Por el momento estamos desarrollando un intrumento que mia la calidad de vida. Lo primero que tratamos de hacer es encontrar una definición de "calidad de vida". En el presente articulo intentamos definir este término en ralación con las personas con deficie3ncia intelectual. Adoptamos un enfoque combinado, según el cual la calidad de vida está constituida por factores específicos objetivos y subjetivos, y partimos de lo publicado sobre discapacidades, de las reflexiones de las ciencias sociales y del análisis filosófico.

Keywords: mental retardation, quality of life, measuring

Introduction

Quality if life is widely considered as a promising indicator of the quality of care for people with mental retardation (see Janssen and Vreeke, 1995).* Quality of life is an encompassing concept that pertains to the heart of the process of care: to allow persons with a mental handicap to have a good life (see Goode, 1990).

But what is it that makes the life of people with mental retardation of high quality? This is a question that must be answered by everyone who intends to measure the quality of life, be it as an indicator for the quality of care of for other reasons (see Landesman, 1986; Rosen, 1986; Dossa, 1989; Schalock, 1990; Parmenter, 1992).

Answering this question has proven to be notoriously difficult. Most researchers in the field of disability look for guidance in the social sciences, where investigation of quality of life has a somewhat longer tradition. Within that tradition a distinction is made in terms of objective and subjective approaches. An objective approach mainly focuses on the environment, which can be measured with the aid of social indicators. A subjective approach is directed at experiences, which are usually measured by psychological indicators. Recently a third approach is gathering attention, the combined or mixed approach, according to which one ought to define quality of life as a mixture of subjective and objective components.

In this paper we want to give further meaning to the combined approach. We feel that an adequate approach of 'quality of life' should encompass the perspective of a person with mental retardation, but should also reflect what can be considered a good life from a (more) external point of view. While it is true that the combined approach is by now the most dominant in the field, we also feel that existing approaches have not gone far enough in delineating the concept of quality of life from this angle. In order to do a better job, that is to say to give a more elaborated picture, we will rely on recent work in the social sciences and more specifically on philosophical analyses of the concepts of quality of life and well-being. We do so by looking for elements in both objective and subjective approaches that are indispensable for obtaining a complete picture of the quality of life of a person with mental retardation.

In order to illustrate the fruitfulness of our approach we will describe the instrument we have developed in order to measure the quality of life of people with mental retardation in residential and semi-residential settings.

*Some people oppose the use of the term 'quality of life' entirely, mainly because this notion is also used in the context of life and death decision making (e.g. Luckasson, 1990; Wolffensberger, 1994).

The objective approach†

According to an objective approach only objective components define the quality of life. Which components should we concern ourselves with?

Objective measurement

Within the framework of an objective approach 'objectivity' is sometimes equated with objective measurability. This type of approach focuses mainly on the (objectively measurable) circumstances in which people find themselves. Quality of life, according to this view, equals living in favourable circumstances (see Drewnowski, 1974; Liu, 1974; for an example in the field of disability research, see Lippman, 1976).

In order to judge if someone is living under favourable life conditions, there is no need to consider his experiences or state of mind. Judgements in terms of quality of life, that are based upon an approach such as this, can be relatively straightforward. There is no need for complying with all sorts of possible misconceptions people have when their own life is concerned, nor is there a need to provide complex interpretative categories that truly mirror psychological states. Some researchers hold that arriving at valid and reliable measurements that are able to differentiate between individuals or between groups, compels one to make use of this type of objective approach (see Parmenter, 1992).

This approach, however, does not answer the question of how we should understand quality of life. It only states that a good life consists of living under favourable conditions. This calls forward the question of how to understand 'favourable conditions'. When there is no further elucidation of the notion of 'favourable life conditions', one cannot exclude the possibility that this approach masks widely diverging ideas concerning the quality of life. Favourable life conditions can be equated with material well-being, for instance, but also with circumstances that provide opportunities for development and mental growth. Research that starts from such an minimal definition differs widely. Liu's (1974) list of favourable circumstances, for instance, differs from the list of Drewnowski (1974). The availability of data seems to play a part here.

There is yet another difficulty with this type of approach. It is a legitimate question as to whether people living under favourable life conditions actually live a good life. Life conditions provide opportunities. They allow people to realize their life plans or to become happy. But favourable life conditions by themselves do not guarantee a good life. Even if circumstances are good on all accounts, some people will lack perseverance to achieve their life goals. Others will struggle with mental problems that prevent them from using opportunities for happiness. In short, favourable life conditions are probably a necessary condition for living a good life, but they are not sufficient.

In view of these problems, should we adopt this approach in order to define the quality of life of people with mental retardation? We cannot envisage a positive role for objective measurement as explained above. The notion of favourable life conditions lacks specific content, but even if we could provide a suitable explanation, it still is questionable as to whether quality of life should concern life conditions only. This approach, thus, does not give us a firm enough grip upon the question of what the quality of life for handicapped people consists of.

†The meaning of the term 'objective' has different connotations in the approaches we distinguish. They have in common that 'quality of life' is defined from an external point of view (out of philosophical, practical or methodological reasons).

However, there are other approaches that can also be labelled as 'objective'. We will look at the basic needs approach first.

Basic needs

The concept of 'needs' – sometimes with 'basic' attached to it – figures predominantly in various analyses of 'quality of life' (see Galtung, 1980; Allardt, 1993; for use in the field of disabilities see Brown, 1988; Goode, 1990).

Needs in general (including basic needs) presuppose an aim or goal that is realized with the satisfaction of the need. Basic needs are (conceptually) connected with harm: when basic needs are not satisfied an organism will suffer. A plant that does not get water will eventually die. And when people lack rest or sleep, for a longer period of time, they inevitably will get ill. Basic needs are furthermore inescapable. There is nothing that people can do, or could have done in the past, to get rid of their basic needs (Thomson, 1987). The fact that people are equipped with certain basic needs is given by human nature (Liss, 1994). Basic needs are universal and in this sense objective, that is to say connected with the specific interests of persons.

A notable problem of the basic needs approach is to determine which needs are really basic. Physical and certain material needs are uncontroversial. Everyone needs shelter, food, sleep, warmth and the like. In the literature, however, a fair amount of leisure time, personal development and freedom of mind, among other valuable goods, are also considered to be basic needs (see Allardt, 1993). When people are not given the opportunity for personal development or when their freedom is severely limited, so the argument goes, then a fundamental aspect of the human person is denied to bloom and this considerably causes harm to one's mental health.

If one takes a more severe approach towards basic needs, only considering non-controversial material and physical needs to be basic, then it is hard to maintain that a life in which basic needs are cared for, already exemplifies a good life. One can interpret 'quality of life' in a minimal sense, but it seems to make more sense to say that one who is able only to satisfy his or her basic needs, realizes a minimal quality of life. Stated in this way the satisfaction of basic needs is important for the quality of life, but it also implies that quality of life in the full sense requires more than the satisfaction of basic needs. Knoll (1990) noted that the concept of quality of life became in vogue only after the care of the mentally retardation was no longer restricted solely to the satisfaction of (basic) material and physical needs.

If one interprets basic needs in a rather broad sense, one can maintain with reason that the realization of these needs provides a good life. The problem now is to persuade others that personal development, freedom, creativity, and so on, are indeed basic needs (and thus an inalienable feature of common human nature). But does frustration of these needs inevitably harm vital human functions? Is there some sort of inner necessity for persons to develop their creative powers?

Some authors rely on the theory of Maslow to persuade us to embrace a broad interpretation of basic needs (see McCall, 1975; for uses in the field of disabilities see Rosen, 1986). This theory, however, does not fare well empirically (see Wahba and Bridwell, 1976). As far as we can see, there is no credible theory of basic needs that supports a broad interpretation of basic needs.

The basic needs approach is thus uncomfortably situated for clarifying the concept of 'quality of life'. When a minimal interpretation is put forward, there is no discussion as to what counts as a basic need, but at the same time it is clear that the satisfaction of basic needs does not tell us very much about the quality of life. When one opts for a more broad interpretation of basic needs, the relation with quality of life is more obvious, but then it is hard to defend the considered needs as basic needs, or for that matter as needs in any genuine sense. And if this is not possible, a ('basic') need approach – thus explained – can hardly be considered an objective approach.

Is it possible to maintain that 'the satisfaction of basic needs' provides an adequate approach to the quality of life of people with mental retardation? In contrast to the explanation of quality of life in terms of favourable life conditions, this approach does give us some clues in understanding quality of life. It will be hard, however, to defend a broad interpretation of basic needs. It is questionable whether (all) persons with mental retardation in effect have the needs they should have according to a broad basic needs approach (Rosen, 1986). Because doubts like these are reasonable, it is wise not to give 'basic' needs an objective status.

This implies that an objective approach of quality of life of people with mental retardation can (and should) opt for a strict basic need approach. For it is clear that the life of a person with mental retardation is certainly not good if his or her basic needs are not met. Attending to the basic needs of the severely mentally handicapped will require considerably more effort (and research) than with less severely handicapped people. For people with severe handicaps it is probably true that the way in which their basic needs are attended to equals their quality of life (see Rosen, 1986; Van Gennep, 1994). In other cases, however, the satisfaction of basic needs surely does not equal a good life. The satisfaction of basic needs should be interpreted as a prerequisite for the quality of life.

There is, however, yet another objective approach that perhaps can supply further components for understanding the quality of life of people with mental retardation.

Objective lists

The last objective approach we will consider is the 'objective list approach'. According to this type of approach quality of life should be understood in terms of the realization of specific goods and values. The objective list approach differs from the basic needs approach in that the considered goods and values do not have to be related to human needs or human nature. Examples of the values and goods concerned are: parenthood, spending time with friends and family, the enjoyment of good art and ethical conscientiousness (see Parfit, 1984; Scanlon, 1993). The person whose quality of life is to be judged does not necessarily have to value these goods. Objective lists mainly provide standards of what a good life should consists of. As worked out in the philosophical literature, this approach does have an elitist slant to it. However, other ways of working out the objective list approach are clearly possible. In the case of the mentally retarded, standards like these are already functioning. Normalization criteria, for example, provide a picture of good life for people with a mental handicap, which is surely not elitist (see Wolfensberger and Thomas, 1983).

The objectivity of this approach is that it provides an a priori constructed list of valuable goods. In order for this approach to be more than a random collection of values or preferences, an objective list should be based upon an idea concerning the good life.

Aristotle's conception of the good life provides an example. His conception is based upon a careful analysis of the problems everyone inevitably encounterers in his or her life: the distribution of goods, exposure to temptations, disturbances in relationships, bad luck, and so on. To live a good life, according to Aristotle, demands the possession of certain traits of character or virtues (justice, perseverance and so on). These personal characteristics enable people to deal adequately with these types of problems and thus provide them the means to live a good life (see Nussbaum, 1993). A quite different base for an objective list is provided by Flanagan (1978, 1982). This author documented what people considered important events in their life, by conducting a large-scale empirical research. In turn Flanagan clustered these events and provided a 'list' that can be used in order to determine whether someone has his or her share of what people generally consider important events in their life.

Generally speaking, an objective list can function as a counterbalance for the way in which people tend to experience their own lives. In many cases what people experience tends to accommodate to the situation in which they find themselves regardless of their level of welfare (see Olson and Schober, 1993; see also Veenhoven, 1991).

The objective list approach is subject to important criticism. In the first place it is argued that quality of life primarily is a question of subjectivity. This objection also applies to the aforementioned approaches, but is felt more strongly here. For according to an objective list approach it is possible that John does not lead a good life because he (for example) is not able to enjoy art, has a dull job, has only a few friends and lives in a poor neighbourhood. John, by the way, is perfectly satisfied with his life, including his work, friends and the like. Critics consider this possibility to be the greatest problem for the objective list approach. The way in which someone experiences his life, his or her own sense of well-being, is the heart of his/her quality of life. The presence of certain (external) norms and values, is only relevant as far as they are deemed important by the person himself.‡

Another difficulty is especially important for people with mental retardation. Suppose an objective list contains norms and values that someone is unable to realize, simply because he lacks the (cognitive) abilities to do so. Does this imply that this person cannot live a life of high quality?

Can an objective list be one of the components of the quality of life of people with mental retardation? So far, we have only considered the satisfaction of basic needs as part of the quality of life. We believe, however, than an objective list can be a fruitful extension, provided that such a list conforms to certain requirements. It will have to be a list that does three things at the same time. First, it must provide a general picture of the quality of life (for example, the way in which non-handicapped people in democratic countries can organize their own lives). Second, it also has to draw attention to issues that are of special importance to people with mental retardation. Third, the list will have to make some sort of provision for the fact that people with mental retardation are unable to realize certain goods and values in their lives. If we possess such a list, we do not have to rely upon the experience of the mentally handicapped themselves in order to judge the quality of their lives.

‡The way we explained the objective list approach allows for the possibility of constructing a list that states all the things people in general *like* and *want*. Yet, even in this case, the criticism from the subjective point of view holds: even if people in general enjoy exercise or having a well paid job, I personally might not.

What should an objective list look like? Measuring quality of life of people with mental retardation, with the aim of improving their lives, takes place within the context of care provision in which the interests and values of different groups play a part (such as those of the individual care providers, parents, insurance agencies and governmental representatives). In this type of situation it is rather unlikely that a specific theory or conception of the good life will be acceptable to all parties. Given the fact that a theory or conception with more than a minimal content would be hard to argue for anyway, it is probably best to strive for a list that has inter-subjective support. All those concerned with people with mental retardation must agree on such a list. It is very important that in the process of arriving at a particular list, certain guidelines concerning reliability and validity are built in.

Do we, by now, have a complete picture of the quality of life of people with mental retardation? Certainly not. It is clear that our approach, thus far, lacks references to the subjective aspects of life. Surely, matters such as happiness, pleasure, satisfaction, valuing one's own life, are unmistakably a central part of the quality of life of people with mental retardation. As different authors have made clear, the importance of the quality of life concept, in the field of disability research, is its potential to articulate the perspective of the mentally retarded themselves (see Parmenter, 1992).

Next, we will look at the subjective approaches that are distinguished in the literature.

Subjective approaches

Generally speaking, a subjective approach of quality of life concerns the subjective perspective of the person in question. His or her experiences, desires and preferences are the only relevant phenomena. External values and norms are irrelevant.

In literature concerning quality of life, different terms are used to refer to the subjective aspects of quality of life: life satisfaction, contentment, happiness, pleasure, the satisfaction or fulfilment of preferences, desires or life plans. These approaches can be headed under three general categories: the satisfaction approach; the experiential approach (sometimes also called the 'mental state approach') and the desire fulfilment approach.

The satisfaction approach

'Quality of life' is frequently equated with life satisfaction (see Campbell *et al.*, 1976; Andrews and Withey, 1976). This is also the case in the field of disabilities (see Ouellete-Kunz, 1990; Cummins, 1991; Rosen *et al.*, 1995).

Surely 'quality of life' and 'life satisfaction' cover a lot of the same territory, especially if one already has opted for a subjective approach to quality of life. When someone is satisfied with his/her life, clearly he or she will experience his or her life as good. Thus 'life satisfaction' seems a good explanation of 'quality of life' (subjectively speaking). The problem, however, is that people in their judgement concerning satisfaction with life, can focus on different things: on the amount of pleasure or happiness they experience, on the extent in which they satisfy their desires, or perhaps even on an irrelevant factor such as their present mood. This implies that in a satisfaction approach there is no further elucidation of the concept of quality of life (except of course the choice of a subjective perspective). We can solve this problem by giving further meaning to the notion of 'life

satisfaction'. Following this lead should bring us to an experiential approach or a desire fulfilment approach. Because of this, we will restrict ourselves to these approaches.

The experiential approach

According to the experiential approach, quality of life should be understood in terms of a positive balance between positive experiences (such as pleasure and happiness) and negative ones (such as pain and sorrow).

According to a classical experiential approach, experiences have one type of quality in common that is crucial for well-being (see Sandoe and Kappel, 1994). Hedonistic theories label this type of experience as 'pleasure'. So the common factor in pleasurable experiences is the quality of pleasantness. How should we understand this type of quality? Is there necessarily a common factor in reading an interesting book, in drinking a glass of good wine, enjoying a game of football or running in the woods? These things are all pleasurable, but do not necessarily have an identifiable common factor to account for the pleasure involved. If such an element cannot be found, then a personal account of pleasure seems more appropriate, and this yields a desire fulfilment account. This, then, means that the experiential approach loses its claim for elucidating the notion of 'quality of life'; this honour should be completely passed on to the desire fulfilment account. However, according to more recent analyses, quality of life can be explained in terms of pleasure (or some equivalent such as happiness), even if one lets go of the presupposition that pleasure has to be an intrinsic property of certain experiences. According to Kagan (1992) we can view pleasure (or its equivalent) as a dimension on which experience can differ. Much in the same way as different types of sound can be measured according to a single dimension such as volume, all sorts of experiences can be assessed according to the dimension of 'pleasure'. The experiential approach sees quality of life as a matter of scores on the dimension of pleasure (or a comparable one).

Because the desire fulfilment approach is sometimes seen as encompassing pleasurable experiences, it is necessary to give some reasons for including this approach in explaining 'quality of life'. In the first place, it is not all that obvious that pleasurable experiences are necessarily related to desires or preferences. To have desires or preferences presupposes certain cognitive abilities that do not have to be assumed when pleasure is concerned (we return to this later on).

Secondly, the relatedness of pleasure and desires or preferences does not necessarily have to lead to skipping one of these categories in order to achieve an understanding of quality of life. Maybe it is true that a further understanding of pleasure requires help from notions like desire and preference. On the other hand, a reason for having a certain desire or preference, can certainly be the pleasure of the experience involved. From this perspective pleasure seems the most crucial factor concerning subjective well-being (see Kagan, 1992).

In what way can this approach help us to understand the quality of life of people with mental retardation?

In general, having pleasurable experiences is considered an important part of the good life. This of course is also true for people with mental retardation. In recent literature the importance of the experiences of people with mental retardation is also stressed for a different reason (see Parmenter, 1992). When it comes to experiences they are the experts. They are in the best possible position to show what is to their liking. And if the care they

receive is more tuned to their true pleasures, this certainly can help in achieving a better quality of life.

The experiential approach, as compared to a desire fulfilment approach, also has the advantage of providing a starting point for gaining insight into the way in which people with severe mental retardation experience their own lives. Care providers and parents are often very good at recognizing when severely handicapped persons have pleasure and when they are in pain (see Egberts, 1985).

The experiential approach, however, also has limitations. This approach does not seem to allow enough room for all the things people with mental retardation deem important. As long as these things relate to experiences, the required space is present, but not all that is considered valuable, relates to experiences, or is considered valuable because of experiences. Most people do not want to be deceived, even though they might never notice when someone has actually misled them. Some people do not eat meat, not because they dislike it, but because they think it isn't right to eat meat as long as animals live a miserable life because of our consumption patterns. People with mental retardation in many cases do attach importance to certain issues that do not necessarily relate to experiences.

In short, the experiential approach does offer a fruitful extension to our approach of quality of life. It, however, lacks room for issues that people with mental retardation might consider valuable. Maybe the desire fulfilment approach can fill this gap.

The desire fulfilment approach

According to a desire fulfilment approach, quality of life pertains to the extent in which a person realizes his or her desires. This does not mean all of his (or her) desires, but only those that are relevant for his or her well-being (see Griffin, 1986). This implies that these desires should (a) be related to personal matters and aims and (b) be rational to a certain extent. To illustrate the first point of concern: imagine an architect talking to a painter at a congress. At the end of their conversation the architect sincerely wishes the painter success within his career. As time passes he forgets the painter. In reality the painter fares well: he has gathered new inspiration and starts to sell his work. According to a unlimited desire fulfilment theory, the quality of life of the architect has now improved. But this surely is implausible. Only when a desire is related to a personal matter or aim, can one expect it to have a genuine effect on a person's well-being (this would have been the case had the painter been a close friend or a relative). Now, concerning the demand of rationality: this demand is necessary because the fulfilment of irrational desires surely will not amount to one's well-being. Suppose someone with little musical talent has the desire to become a famous pianist. Apart from luck and lots of practice, becoming a famous pianist surely requires a larger amount of musical talent. The desire to become a famous pianist, whilst lacking the necessary talent, is irrational. Acting upon that desire will in all probability not bring about happiness.

The experiential approach is different from the desire fulfilment approach in at least two ways. In the first place the reach of the last-mentioned is larger: according to a desire fulfilment approach quality of life can also be influenced by things we do not experience or wherein experiences are not of central importance. In the second place, values usually play a considerable part in a desire fulfilment approach. In many cases we desire certain things because we value them, not only because they bring us pleasure. This implies that

a desire fulfilment approach has to take account of the evaluative viewpoint of the persons being assessed.

Should we take the fulfilment of desires to be a component of the quality of life of persons with mental retardation?

The experiential approach, as we have just seen, offers the possibility of expressing the subjective perspective of people with mental retardation. But this type of approach has its limitations. Certain subjective aspects of people's lives cannot be expressed by it. The desire fulfilment approach fills this gap: it can take account of the values people subscribe to and of things that are important to people, that do not correspond to experiences. This approach, therefore, offers a sensible broadening of our approach of quality of life of people with mental retardation.

The quality of life of people with mental retardation

In this paper we have arrived at a new approach to the quality of life of people with mental retardation by combining the sensible components of other, in themselves more limited, approaches. According to this new approach, the quality of life of people with mental retardation consists of four components. From an objective point of view the quality of life of a person with mental retardation consists of: (a) the extent to which he or she can satisfy his or her basic needs (understood in the minimal sense); (b) the extent to which he or she has the opportunity to realize – inter-subjectively agreed upon – goods and values. From a subjective point of view the quality of life of a person with mental retardation consists of: (c) the extent to which he or she experiences pleasure and happiness in his/her life (as opposed to pain and sorrow); (d) the extent to which he or she can realize his or her personal and rational desires.

In our research project these four components generated a model of the quality of life of people with mental retardation. This model became the basis of a questionnaire. In the following, we want to show in what ways our approach helped us to shape our model as well as our questionnaire.

Our model is based upon a division of 'life' into different domains. A domain is understood as an part of life that can be seen as relatively autonomous. A survey of and comparison of existing classifications, led us to distinguish the following domains: the physical domain, the personal domain, the material domain, the domain of relationships, the domain of leisure and recreation, the domain of employment, education and daily activities, and the domain of societal integration and participation. The domains are further divided into sub-domains. The personal domain, for instance has as its sub-domains: psychological well-being, identity and one's religion or philosophy on life. In broad outline our classification follows that of Flanagan (1982).

Within each (sub)domain the four components we mentioned in our approach play a major apart. Consider the physical domain. Objectively speaking people have certain basic needs: food, drink, sleep, exercise, clean air, and so on. From an objective perspective we can furthermore say that within this domain certain goods and values are of importance: privacy, respectful care, the freedom to choose, the development of skills, etc. In the objective part of our 'quality of life' questionnaire, we systematically check if people with mental retardation can satisfy their basic needs and realize the values that are important for them, in each (sub)domain. The items in the objective part of our questionnaire are formulated with the aid of different types of experts: people who in various ways are

connected with the care of people with mental retardation: care providers, staff, psychologists, educationalists, people from parental organizations and the health care inspectorate. These people had to reach consensus concerning the items that best mirror quality of life within the different (sub)domains.

Besides the objective part of our questionnaire, there is also a subjective part that measures the subjective component of quality of life. Within each (sub)domain people with mental retardation have certain personal desires and things they find pleasurable or not. In the subjective part of our questionnaire we systematically verify to what extent a person with mental retardation can fulfil his or her personal and rational desires and to what extent he or she experiences pleasure or happiness within the domain in question. The questions in the subjective part of our questionnaire address the same subjects as those of the objective part. While the objective part asks to what extent a certain value is realized (for instance, privacy when taking a bath), the subjective part asks how this element of life is experienced by the person. Does a person with mental retardation experience enough privacy when he or she take a bath? Or does he or she feel watched when he/she is in the bathroom?

At the moment the second version of our instrument is being tested empirically. The methodological aspects (reliability and validity) especially are the object of our test. We are also preparing for a large-scale study in order to document the quality of life of people with mental retardation who live in institutions. In due course publications hereof will follow.

Acknowledgements

This research was funded by Steunfords 's Heeren Loo, Amersfoort, The Netherlands.

References

Allardt, R. (1993). Having, loving, being: an alternative to the Swedish model of welfare research. In *Quality of Life* (edited by M. Nussbaum and A. Sen), p. 94. Oxford: Clarendon Press.

Andrews, F. R. and Whithey, S. B. (1976). *Social Indicators of Well-being: American's Perceptions of Life Quality*. New York: Plenum Press.

Brown, R. I. (1988). Quality of life and rehabilitation: an introduction. In *Quality of Life for Handicapped People* (edited by R. I. Brown), pp. 1–6, London: Croom Helm.

Campbell, A., Converse, P. E. and Rodgers, W. L. (1976). *The Quality of American Life*. New York: Russell Sage Foundation.

Cummins, T. A. (1991). The comprehensive quality of life scale-intellectual disability: an instrument under development. *Australian and New Zealand Journal of Developmental Disabilities*, **17**, 259–64.

Dossa, P. A. (1989). Quality of life: individualism or holism? A critical review of the literature. *International Journal of Rehabilitation Research*, **12**, 121–36.

Drewnowski, J. (1974). *On Measuring and Planning the Quality of Life*. Den Haag & Parijs: Mouton.

Egberts, M. J. A. (1985). 'De wakkere pedagogische intentie': over de opvoeding van diep-zwakzinige kinderent in een inrichting. In *Tussen Verlangen en Werkelijk-heid: Opstellen Over de Waardigheid Van Mensen met een Verstandelijke Handicap* (edited by J. Stolk and M. J. Egberts), pp. 57–76. Meppel: Boom.

Flanagan, J. C. (1978). A research approach to improving our quality of life. *American Psychologist*, **33**, 138–47.

Flanagan, J. C.(1982). Measurement of quality of life: current state of the art. *Archives of Physical Medicine and Rehabilitation*, **63**, 56–9.

Galtung, J. (1980). The basic needs approach. In *Human Needs: A Contribution to the Current Debate* (edited by K. Lederer), pp. 50–125. Cambridge, Mass: Oelgeschlager, Gunn and Hain.

Gennep, A. van (1994). Quality of life of persons with a mental handicap. In *The Quest for Quality: the Evaluation of Helping Interventions* (edited by B. Quarsell and B. van der Linden), pp. 95–108. Amsterdam: SCO.

Goode, D. (1990). Thinking about and discussing quality of life. In *Quality of life: Perspectives and Issues* (edited by R. L. Schalock and M. J. Begab), pp. 41–57. Washington: American Association on Mental Retardation.

Griffin, J. (1986). *Well-being: Its Meaning, Measurement and Moral Importance*, Oxford: Clarendon Press.

Janssen, C. G. C. and Vreeke, G. J. (1995). Outcome indicators in the care for people with a mental handicap. *The British Journal of Development Disabilities*, **XLI**, 79–90.

Kagan, S. (1992). The limits of well-being. In *The Good Life and the Human Good* (edited by E. F, Paul, F. D. Miller Jr and J. Paul), pp. 169–89. Cambridge: University Press.

Knoll, J. A. (1990). Defining quality in residential services. In *Quality Assurance for Individuals with Developmental Disabilities* (edited by V. S. Bradley and H. A. Bersani), pp. 235–61. Baltimore: Paul Brookes.

Landesman, S. (1986). Quality of life and personal satisfaction: definition and measurement issues. *Mental Retardation*, **24**(3), 141–3.

Lippman, L. (1976). Indicators of societal concern for mentally retarded persons. *Social Indicator Research*, **3**, 181–215.

Liss, P. E. (1994). On need and quality of life. In *Concepts and Measurement of Quality of Life in Health Care* (edited by L. Nordenfelt), pp. 63–78. Dordrecht: Kluwer Academic Publishers.

Liu, B. C. (1974). Quality of life indicators: a preliminary investigation. *Social Indicator Research*, **1**, 187–208.

Luckasson, R. (1990). A Lawyer's perspective on quality of life. In *Quality of Life: Perspectives and Issues* (edited by R. L. Schalock and M. J. Begab), pp. 211–14. Washington: American Association on Mental Retardation.

McCall, S. (1975). Quality of life. *Social Indicators Research*, **2**, 229–48.

Nussbaum, M. (1993). Non-relative virtues: an Aristotelian approach. In *Quality of Life* (edited by M. Nussbaum and A. Sen), pp. 242–69. Oxford: Clarendon Press.

Olson, G. I. and Schober, B. I. (1993). The satisfied poor: development of an intervention-oriented theoretical framework to explain satisfaction with a life in poverty. *Social Indicators Research*, **28**, 173–93.

Ouellette-Kunz, H. (1990). A pilot study in the use of the quality of life interview schedule. *Social Indicators Research*, **23**, 283–98.

Parfit, D. (1984). *Reasons and Persons*. Oxford: Clarendon Press.

Parmenter, T. R. (1992). Quality of life of people with developmental disabilities. In *International Review of Research in Mental Retardation* (edited by N. W. Bray), pp. 247–87. vol. 18.

Rosen, M. (1986). Quality of life for persons with mental retardation: a question of entitlement. *Mental Retardation*, **24**, 365–6.

Rosen, M., Simon, E. W. and McKinsey, L. (1995). Subjective measures of quality of life. *Mental Retardation*, **33**, 31–34.

Sandoe, P. and Kappel, K. (1994). Changing preferences: conceptual problems in comparing health-related quality of life. In *Concepts and Measurement of Quality of Life in Health Care* (edited by L. Nordenfelt), pp. 161–80. Dordecht, Boston & London: Kluwer Academic Publishers.

Scanlon, T. M. (1991). The moral basis of interpersonal comparisons. In *Interpersonal Comparisons of Well-being* (edited by J. Elster and J. E. Roemer), pp. 17–44. Cambridge: Cambridge University Press.

Scanlon, T. M. (1993). Value, desire, and quality of life. In *Quality of Life* (edited by M. Nussbaum and A. Sen), pp. 185–200. Oxford: Clarendon Press.

Schalock, R. L. (1990). Preface. In *Quality of Life: Perspectives and Issues* (edited by R. L. Schalock and M. J. Begab), pp. ix–xii. Washington: American Association on Mental Retardation.

Schalock, R. L., Keith, K. D., Hoffman, K. and Karan, O. C. (1989). Quality of life: its measurement and use. *Mental Retardation*, **27**, 25–31.

Thomson, G. (1987). *Needs*. London and New York: Routledge & Kegan Paul.

Veenhoven, R. (1991). Is happiness relative? *Journal of Social Indicators Research*, **24**, 1–34.

Wahba, M. A. and Bridwell, L. G. (1976). Maslow reconsidered: a review of research on the need hierarch theory. *Organizational Behaviour and Human Performance*, **15**, 212–40.

Wolfensberger, W. (1994). Let's hang up 'quality of life' as a hopeless term. In *Quality of Life for Persons with Disabilities: International Perspectives and Issues*, pp. 225–321. Cambridge, MA: Brookline Books.

Wolfensberger, W. and Thomson, S. (1983). *Passing (Program Analysis of Service System Implementation of Normalization Goals); Normalization Criteria and Rating Manual*. Ontario: National Institute on Mental Retardation.